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**Artificial reproductive technologies and the right to the truth
about genetic and biographic origins
Ludovica Poli***

1. Introduction

The paper aims to examine the right of people conceived through artificial reproductive technologies (ART) involving a third party's contribution to know their origins.

The analysis begins with a general introduction to ART and considers their impact on family as a social construct (2). It then ponders the double dimension of the right considered, namely the right to know *genetic* origins, which appears especially relevant in the current post-genomics era (3), and the right to know *biographic* origins (4). The paper proceeds considering the legal foundations of this right under international law (5.1), envisaging - in view of the case-law of the European Court of human rights (ECtHR) - possible principles to be applied in balancing it with other competing interests (5.2). It finally explains that the *conditio sine qua non* for a full exercise of the right to know personal origins is the awareness of the means of conception, a responsibility which rests upon the recipient parents, with only a residual role for the State (6).

2. ART and the use of technology to generate children (and families)

Artificial reproductive technologies include a number of treatments involving *in vitro* handling of human gametes (eggs and sperm) and embryos to establish a pregnancy.

Since the birth of the first baby resulting from *in vitro* fertilization (IVF) in 1978, these methods strongly and constantly improved: nowadays techniques such as gamete donation, surrogacy, embryo cryopreservation¹ and embryo donation are common in many States around the world and many other improvements are here to come in the near future. Numbers reveal also that ART represents a growing business², with an international dimension: many patients travel to other countries to undertake fertility treatments not available to them in their own state for a number of reasons, fueling the phenomenon of 'reproductive tourism'³.

Aiming at generating a child, ART have a key impact on family as a social construct, only partially similar to adoption. In fact, while adoption is a normative and social instrument to create a family, ART involve a technical intervention in what has been for centuries considered exclusively a natural process, as they permit the separation of procreation from sexual intercourse. As such,

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¹ Embryo cryopreservation is the process of preserving an embryo at sub-zero temperatures, (generally at an embryogenesis stage) and it used for extra embryos. It also can be used to postpone the pregnancy for a number of reasons (of medical or different nature).

² According to the European Society of Human Reproduction and Embryology, it is now estimated that more than 5 million babies have been born worldwide since 1978 (<https://www.eshre.eu/Guidelines-and-Legal/ART-fact-sheet.aspx>)

³ R.F. STORROW, *Quests for Conception: Fertility Tourists, Globalization and Feminist Legal Theory*, in *Hastings Law Journal*, vol. 57, 2005-2006, pp. 295 ss.; G. PENNING, *Reproductive tourism as moral pluralism in motion*, in *Journal of Medical Ethics*, vol. 28, 2002; pp. 337 ss.; G.K.D. CROZIER, D. MARTIN, *How to address the ethics of reproductive travel to developing countries: a comparison of national self-sufficiency and regulated market approaches*, in *Developing World Bioethics*, vol. 12, 2012 pp. 45 ss..

ART not only allow, analogously to adoption, ‘the creation of families that otherwise would not exist’⁴, but they also offer ‘alternative routes to family life, creating biological linkages that adoption bypasses’⁵. Additionally, while adoption is mainly conceived at the benefit of parentless children, ART help adults to realize their aspiration of becoming parents⁶. More than adoption, thus, these techniques permit ‘a remarkable pluralism of family structures’⁷. Single parents, same-sex couples and older women are now able to found a family with children genetically related to them.

As WALDMAN states: ‘for some, the explosion of ART-inspired families is cause for celebration; for others, it signals the subversion of important social values. But regardless of whether one embraces or reviles the trend, the proliferation of non-traditional baby-making poses a multitude of questions’⁸. This paper aims at analysing one of these issues, namely the right of ART-conceived people to know their origins. This question is relevant in any case of ‘third-party reproduction’, that is when (at least part of) the genetic material is provided, or the gestation is carried out, by a person other than the parent(s) who will take care of the resulting baby. These methods include:

- a) heterologous fertilization, entailing sperm/egg donation or the so-called ‘spindle transfer’, a genetic manipulation technique consisting in the use of the future mother’s nuclear DNA and the mitochondrial DNA coming from a donor⁹;
- b) embryo donation, in which leftover embryos - produced *in vitro* during a fertility treatment but not implanted in the maternal womb - or embryos specifically created for donation (using donor eggs and donor sperm) are provided to future parent(s);
- c) surrogacy, involving a woman (the surrogate) carrying the pregnancy for intended parents; in this case, a third donor’s oocyte is usually used to produce the embryo; more rarely the surrogate mother donates her ova. In few cases, the oocyte comes from the social mother, the woman who will take care of the resulting baby.

Whenever half of, or the entire genetic makeup comes from donors, resulting children might nourish an interest in knowing certain data of their biological ascendants, in order to assess their *genetic* origins. In addition, in case of surrogacy, resulting children might be interested in knowing other relevant circumstances of their birth, even when they are not genetically related to the surrogate. As their existence would not have been possible without the surrogate’s contribution, some of her data might appear essential to them, to retrace their *biographical* origins.

3. Genetic origins in the post-genomics era: new needs generated by new technologies

Developments in medical science not only help to overcome barriers seemingly undefeatable, they also drive important changes in the society’s prevalent perceptions. As a matter of fact, while ART permit to ‘accord’ parenting to people who would not otherwise have a genetically related

⁴ M. SABATELLO, *Are the kids all right? A child-centred approach to assisted reproductive technologies*, in *Netherlands Quarterly Human Rights*, vol. 31, 2013, pp. 74-75.

⁵ E. WALDMAN, *What do we tell the children?*, in *Capital University Law Review*, vol. 35, 2006, p. 517.

⁶ K.W. RUYTER, *The example of adoption for medically assisted conception*, in D. EVANS (Ed.), *Creating the Child. The ethics, law and practice of assisted procreation*, Martinus Nijhoff, The Hague, 1996, p. 180.

⁷ M. SABATELLO, *op. cit.*, p. 75.

⁸ E. WALDMAN, *op. cit.*, p. 517.

⁹ This technique aims at preventing mitochondrial diseases: P. AMATO, M. TACHIBANA, M. SPARMAN, S. MITALPOV, *Three-Parent IVF: Gene Replacement for the Prevention of Inherited Mitochondrial Diseases*, in *Fertility and sterility*, vol. 101, 2014, pp. 31-35.

offspring, the possibility to trace genetic identity through a DNA test, feeds an 'in-built need to know the "truth" about personal roots'¹⁰.

A critical role in this regard has been played by the Human Genome Project, a publicly funded program initiated in 1990, with the objective of determining the DNA sequence of the entire euchromatic human genome, and declared complete in 2003¹¹. The consequences of this achievement are visibly enormous: the capacity to genetically predict personal risks of diseases and responsiveness to drugs, as well as the possibility to develop gene-based medicaments are having a revolutionary impact on the practice of medicine¹², but also on personal expectations. Since a detailed analysis of the genetic makeup explains current pathological conditions and predicts likely future developments, knowing genetic origins implies a better treatment and a more likely successful prevention of diseases. As a consequence, people consider this information basilar to preserve health and, more in general, to enjoy a full psycho-physical wellbeing.

Additionally, the entrance 'into the new genetic era, marked by the Human Genome Project'¹³ alimanted the idea that biological origins are crucial to define identity and kinship ties: the meaning of tracing these origins is closely linked to the construction of the self, through a complete definition of the individual's narrative identity¹⁴.

Clearly this process is not free from potential deviations. In a society 'obsessed with tracing its ancestors'¹⁵, 'the gene has been seen as the "unifying concept" of the field of biology, with a virtually "iconic status" that makes it capable of explaining us to ourselves'¹⁶ and DNA has become 'a contemporary soul, the site of identity and self'¹⁷. As a consequence, 'people tend to see genetic information as more definitive and predictive than other types of data'¹⁸. Such genetic determinism or essentialism¹⁹ generates 'an un-warranted sense of inevitability'²⁰ and may finally

¹⁰ J. FORTIN, *Children's right to know their origins - too far, too fast?*, in *Child and Family Law Quarterly*, vol. 21, 2009, p. 341.

¹¹ The majority of the funding for the United States human genome project came from the US Department of Energy and the National Institute of Health. The program later evolved into an international effort involving research facilities in France, Germany, Japan, the United Kingdom and the United States.

¹² F.S. COLLINS, V.A. MCKUSICK, *Implications of the Human Genome Project for Medical Science*, in *JAMA*, vol. 285, 2001, pp. 540-544. Since the beginning, the Human Genome Project supported an ethical, legal and social implications research program to address the many complex issues that might arise from this science: see J.E. McEWEN, J.T. BOYER, K.Y. SUN, K.H. ROTHENBERG, N.C. LOCKHART, M.S. GUYER, *The Ethical, Legal, and Social Implications Program of the National Human Genome Research Institute: Reflections on an Ongoing Experiment*, in *Annual Review of Genomics and Human Genetics*, 2014, pp. 481-505. Much attention has been paid on the possible misuse of genetic information, in particular resulting in discrimination in the field of health or insurances, as well as in the workplace: E. WRIGHT CLAYTON, *Ethical, Legal, and Social Implications of Genomic Medicine*, in *New Engl J Med*, vol. 349, 2003, p. 563.

¹³ T. FREEMAN, M. RICHARDS, *DNA Testing and Kinship; Paternity, Genealogy and the Search for the 'Truth' of our Genetic Origins*, in F. EBTEHAJ, B. LINDLEY, M. RICHARDS (Eds.), *Kinship Matters*, Hart Publishing, Oxford, 2006, p. 79.

¹⁴ Narrative identity is 'the internalized and evolving story of the self that a person constructs to make sense and meaning out of his or her life': D.P. MCADAMS, *Narrative identity*, in S.J. SCHWARTZ, K. LUYCKX, V.L. VIGNOLES (Eds.), *Handbook of identity theory and research*, Springer, New York, 2011, p. 99.

¹⁵ J. FORTIN, *op. cit.*, p. 343.

¹⁶ N. CAHN, *Children's interests and information disclosure: who provided the egg and sperm? Or mommy, where (and whom) do I come from?*, in *Georgetown Journal of Gender and the Law*, vol. 2, 2000, p. 17.

¹⁷ D. NELKIN, M. S. LINDEE, *The DNA mystique. The Gene as a Cultural Icon*, University of Michigan Press, Ann Arbor, 2004, p. 49.

¹⁸ E. WRIGHT CLAYTON, *op. cit.*, p. 563.

¹⁹ 'A concept which suggests that a person is merely the sum of her genes, and behavior can be predicted based on genetic information': N. CAHN, *op. cit.*, p. 17.

²⁰ E. WRIGHT CLAYTON, *op. cit.*, p. 563.

cause the risk to perceive blood kinship as superior to adoptive relationships²¹, or push children 'to find their "parents", not necessarily because of a "natural" desire to know their origins, but because such a desire is constructed, recognized, and legitimized by the law'²².

However, even despite these questionable profiles, the assessment of certain scientific data is becoming an easy and fast process and seeking this kind of information is rapidly turning in a routine expectation for everyone.

4. *Surrogacy and biographic origins*

The key importance of genetic information for health and personal identity, however, does not exhaustively portray the contents of the right of ART-conceived people to know their origins. In this perspective, it is interesting to note that adoptees trying to trace their origins are usually more interested in finding the birth mother, rather than both the biological parents. As CAHAN explains, 'genetics provides only a partial explanation for the search process'²³.

Therefore, even for ART-conceived people, the desire to assess personal origins may implies an additional dimension, covering other relevant circumstances of birth, with special reference to the role played by the surrogate mother. Depending upon personal attitude and experience, an individual might feel necessary (or at least desirable) to know the woman who has carried him or her in her womb, in order to better define the perception of the self, and the scope of his/her narrative identity.

The European Court of human rights seems to confirm this conclusion in *Gaskin v. Uk*, stressing the existence of 'a vital interest, protected by the Convention, in receiving the information necessary to know and to understand (...) childhood and early development'²⁴. The case concerned the right of the applicant, who had been placed in public care as a baby, to have access to his complete personal file. The Court decided that people in the applicant's position should not be obstructed from accessing their records confirming that 'the information compiled and maintained by the local authority related to the applicant's basic identity, and indeed provided the only coherent record of his early childhood and formative years'²⁵.

Mutatis mutandis, a similar principle is applicable in the case of surrogacy, especially considering that prenatal attachment²⁶ to the gestational mother might be relevant for the definition of the individual identity.

5. *The right to know personal origins as a fundamental right to be balanced with other prominent positions*

Even in the absence of an autonomous formulation in international treaties, the right to know personal origins falls within the scope of several rights: the child's right to know his/her parents

²¹ N. CAHN, *op. cit.*, p. 17.

²² I. TURKMENDAG, R. DINGWALL, T. MURPHY, *The Removal of Donor Anonymity in the UK: The Silencing of Claims by Would-be Parents*, in *Int'l J. of Law, Policy and the Family*, vol. 22, 2008, 291.

²³ N. CAHN, *op. cit.*, p. 18.

²⁴ European Court of Human Rights, *Gaskin v. United Kingdom*, n. 10454/83, 7 July 1989, para. 49.

²⁵ *Ibidem*, para. 39.

²⁶ M. LAXTON-KANE, P. SLADE, *The role of maternal prenatal attachment in a woman's experience of pregnancy and implications for the process of care*, in *Journal of Reproductive and Infant Psychology*, vol. 20, 2002, pp. 253-266.

and to preserve identity, the right to a private life and to the protection of personal data and the right to health. None of them, however, has an absolute nature: a fair balance with other (collective and individual) interests relevant in each case is thus deemed necessary.

Particular attention should be firstly paid to the position of donors and surrogate mothers, who may claim a right to anonymity. The right to remain unidentified is connected to the protection of their personal data, but it also aims at protecting their private and family life, whenever they want to preserve affective ties from external interference.

As much important are the rights of social (and legal) parents, who usually wish to maintain the donors' and surrogates' anonymity, in order to better preserve the stability of their relationships with children²⁷.

Finally, natural siblings are in a controversial position. On the one hand, they (should) have an objective interest in knowing people sharing - at least in part - their genetic make-up, at any rate to avoid accidental incest. On the other hand, they might demand respect for their private life, including personal data.

The analysis will proceed considering the right to know personal origins through the lens of the different international law provisions covering it. It will then move to envisage potential guidelines for a fair balance with the donors' and/or surrogates' right to anonymity, understood as a right to the respect of private life and personal data. The ECtHR case-law will offer some directions in this regard. While the Court has never decided a case on the right of ART-conceived people to know their origins, principles can be derived from the jurisprudence on the establishment of paternity and on the identification of the birthmother in case of anonymous and secret birth. In both classes of judgements, the Court affirms that people seeking to establish the identity of their ascendants have a vital interest in receiving the information necessary to establish an important aspect of their personal identity²⁸, and that such interest does not decrease with age, quite the reverse²⁹.

5.1 A multifaceted right

First of all, the right to know personal origins can be understood as a specification of the guarantee framed under Article 7 of the Convention on the rights of the child (Child Convention), according which any child shall have, 'as far as possible, the right to know and be cared for by his or her parents'.

This provision has to be broadly interpreted, in particular considering that the term 'parents' embraces genetic parents, birth parents³⁰ and even 'psychological parents', namely 'those who cared for the child for significant periods during infancy and childhood'³¹. However, the wording 'as far as possible' suggests that the identity of a parent may be unknown for a number of

²⁷ C. CAMPIGLIO, *Norme italiane sulla procreazione assistita e parametri internazionali: il ruolo creativo della giurisprudenza*, in *Rivista di diritto internazionale privato e processuale*, vol. 50, 2014, p. 515; Id., *Procreazione assistita e famiglia nel diritto internazionale*, Cedam, Padova, 2003, p. 152.

²⁸ European Court of Human Rights, I Chamber, *Mikulić v. Croatia*, n. 53176/99, 7 February 2002, para. 64.

²⁹ European Court of Human Rights, III Chamber, *Jäggi v. Switzerland*, n. 58757/00, 13 July 2006, para. 40; II Chamber, *Godelli v. Italy*, n. 33783/09, 25 September 2012, para. 56.

³⁰ That is 'the mother who gave birth and the father who claimed paternity through partnership with the mother at the time of birth (or whatever the social definition of father is within the culture: the point being that such social definitions are important to children in terms of their identity)': UNICEF, *Implementation Handbook for the Convention on the Rights of the Child*, 2007 pp. 104-105.

³¹ *Ivi*, p. 105.

reasons³², including cases in which the State itself decides that a parent should not be identifiable (so-called 'state-approved secrecy')³³. Thus, Article 7 'create[s] a presumption in favour of providing children with access to information about their biological parents before they turn 18 where this is logistically possible, that is, if the information is available'³⁴. Worthy of note, egg/sperm donation under anonymity (whenever prescribed or consented by domestic law) is a state-approved secrecy: nevertheless, the UN Committee on the rights of the child argued the possible contradiction between this policy and Article 7³⁵.

The right to know one's own origins is also linked to the right to preserve identity, guaranteed by Article 8 of the Child Convention. This provision contains the first legal recognition of identity as a fundamental right and, notably, at the benefit of children³⁶. This notwithstanding, Article 8 does not provide a sound definition of identity, but it rather mentions three of the aspects that this concept includes (name, nationality and family relations), already enumerated under Article 7. Still, this is not an exhaustive list as 'many other aspects of the child's identity (...) are deemed protected by the provision, for example the child's personal history, (...) race, culture, religion, language and (...) physical appearance, abilities and inclinations'³⁷. As a matter of fact, 'identity' is a very broad concept covering all those elements that allow anyone to assert his/her existence in a society. Identity is a matter of recognition of everybody's individuality, what differentiates any person from his/her peers. Thus, Article 8 includes 'the right to know one's ancestral background, including medical and genetic information about oneself and one's biological parentage, the circumstances of one's conception, time and place of birth, and records of other events meaningful to the individual'³⁸.

Children, obviously, are not the only beneficiaries of the right to know the genetic and/or biographic origins. Rather, this right is more easily exercised in adulthood: therefore, other treaty provisions are relevant to assess it. The right to trace personal origins is connected to the right to the respect of private life, guaranteed by Article 8 of the European Convention of human rights (ECHR), as well as by Article 7 of the Charter of Fundamental Rights of the European Union (EU Charter), and by many other provisions, even under the different wording of 'right to privacy'³⁹. As clarified by the European Court of human rights, the right to the private life covers many different manifestations of a person's existence, seen both as an expression of individuality and as a set of relationships with other people. It is clear that the access to information relating genetic and

³² For example, when the mother does not know who the father is, the child has been abandoned or, the mother refuses to identify the father: 'while mothers could, arguably, be legally required to name the father, it would be difficult to enforce this and conflict could be raised between the mother's rights and the child's rights'. *Ivi*, p. 135.

³³ *Ibidem*.

³⁴ J. TOBIN, *Donor conceived individuals and access to information about their genetic origins: the relevance and role of rights*, Melbourne Legal Studies Research Paper n. 591, 2002, p. 13, available at: <http://papers.ssrn.com>.

³⁵ UN Committee on the rights of the child: CRC/C/15/Add.23 (Norway) 25 April 1994, para. 10; CRC/C/15/Add.182 (Switzerland) 13 June 2002, paras. 28 e 29; CRC/C/15/Add.188 (United Kingdom) 9 October 2002, paras. 31 e 32.

³⁶ G.A. STEWART, *Interpreting the Child's Right to Identity in the U.N. Convention on the Rights of the Child*, in *Family Law Quarterly*, vol. 26, 1992, pp. 221 ss..

³⁷ S. BESSON, *Enforcing the Child's Right to Know Her Origins: Contrasting Approaches Under the Convention on the Rights of the Child and the European Convention on Human Rights*, in *International Journal of Law, Policy and the Family*, vol. 21, 2007, pp. 143-144.

³⁸ M. FREEMAN, A. MARGARIA, *Who and What Is a Mother? Maternity, Responsibility and Liberty*, in *Theoretical Inquiries in Law*, vol. 13, 2012, pp. 159-160.

³⁹ Universal Declaration of human rights, 1948, Article 12; International Covenant of civil and political rights, 1966, Article 17.

biographic origins may significantly influence the harmonious development of each individual's personality, conditioning the way of being of each one, as well as the establishment of connections with others.

The right to know genetic and biographic origins can also be construed as part of the right to the protection of personal data, guaranteed under Article 8 ECHR and specified in other provisions, such as Article 8 of the EU Charter. This right implies a positive obligation upon States to ensure in favor of any individual the access to his/her data, held by public authorities or private persons.

Last but not least, this right is closely related to the right to health, which is founded on a number of different legal provisions, both in universal⁴⁰ and in regional instruments⁴¹. While being a dynamic concept, involving technical and legal different interpretations⁴², the right to health certainly includes the right to have access to relevant information including family medical history, which is particularly important in the case of hereditary diseases. This precise profile is explicitly recognized under Article 10 of the Oviedo Convention, stating that 'everyone is entitled to know any information collected about his or her health'.

5.2 Possible guidelines for balancing competing interests

To identify guidelines for a fair balance between the rights to know genetic/biographic origins and other competing interests, it should be firstly considered whether the person interested in tracing his or her origins is a child or not.

Whenever a minor (once became mature enough) claims to exercise the right to know his/her genetic/biographic origins, the principle of 'the best interest of the child' should be applied to solve potential clashes with competing interests. This principle, envisaged by Article 3 of the Child Convention, implies that the child's best interest shall be a primary consideration in all actions concerning children, taken both by state authorities and by private institutions. The UN Committee on the rights of the child has clarified that it is a threefold concept, being at the same time a substantive right, an interpretative legal principle, and a rule of procedure⁴³, while the ECtHR confirms that it is the guiding principle that drives its decision whenever a child's position is considered⁴⁴.

Despite its undisputed relevance, 'the definition of the child's best interests, (...) is not always obvious, especially in a long-term perspective. (...) [I]t has been argued that what is in the best interests of the child varies from one era to another and also depends on the resources, the

⁴⁰ Universal Declaration of human rights, 1948, Article 25; International Covenant of economic, social and cultural rights and political rights, 1966, Article 12; International Convention on the elimination of all forms of racial discrimination, 1965, Article 5; Convention on the elimination of all forms of discrimination against women 1979, 11 and Article 14; Convention on the rights of the child, 1989, Article 24.

⁴¹ American Declaration of the rights and duties of man, 1948, Article XI; Additional Protocol to the American Convention on human rights in the area of economic, social and cultural rights, 1988, Article 10; African Charter on human and peoples' rights, 1981, Article 16; European Social Charter, 1996, Article 11.

⁴² P. ACCONCI, *Tutela della salute e diritto internazionale*, Cedam, Padova, 2011, p. 5.

⁴³ UN Committee on the rights of the child, General Comment No. 14 on the 'Best Interests of the Child', CRC/C/GC/14, 29 May 2013.

⁴⁴ European Court of Human Rights, V Chamber, *Mennesson v. France*, n. 65192/11, 26 July 2014, paras. 99-100; *Labassee v. France*, n. 65941/11, 26 July 2014, paras. 78-79.

developmental level and the culture of the country in which the child lives'⁴⁵. In this sense, one might conclude that, in order to justify the disclosure of relevant data, the child's interest should be specifically 'qualified'. This would happen, for example, whenever special health reasons militate for a full tracing of the genetic origins.

Nevertheless, in the most recent ECtHR's case-law, the principle of 'the best interest of the child' seems to push the Court to identify not only a right, but even a 'duty' to know personal origins. This is what emerges from the case *Mandet v. France*⁴⁶, in which the domestic courts acknowledged the right of a presumed biological father to have his paternity recognized, deciding that this was in the son's best interests, despite the child (who already had a legal and social father) asked the judges not to change his established family ties. The child claimed a violation of Article 8 before the Court, which rather confirmed the domestic authorities' decision, arguing - as underlined by MERCKX - that 'the interests of the son simply did not lie where he saw them'⁴⁷. According to the Strasbourg judges, domestic courts did not make the position of the biological father prevail over the child's ones, but rather they correctly considered that the interests of both converged⁴⁸.

When the rights of an ART-conceived adult are at stake, on the contrary, it would firstly be necessary to draw a distinction between *non-identifying* and *identifying* data, as the precise contents of the information appears diriment.

In fact, the disclosure of non-identifying data would easily satisfy the interest of the ART-conceived person, while preserving the right to anonymity of other people involved. This is particularly relevant if one considers the right to health of the ART-conceived person. Despite de-anonymization of gamete donors⁴⁹ is usually the best way to guarantee access to genetic information - a key tool in the prevention and treatment of diseases - alternative solutions are certainly feasible⁵⁰. In fact, 'sperm banks have endeavored, and government regulation thereof should push, to make available to the parents of donor-conceived children the fullest possible medical histories'⁵¹. Thus, the right to health of ART conceived person can be satisfied without any interference in the rights of donors/surrogate, in particular without revealing their identity. The disclosure, in this case, should probably include the constant updated of the relevant records, possibly 'contractually enforceable by banks against sperm donors'⁵², which appears an opportune and necessary operation in view of the constant scientific development in detecting diseases and producing medicaments.

⁴⁵ T. HAMMARBERG, *The principle of the best interests of the child – what it means and what it demands from adults*, CommDH/Speech(2008)10, 30 may 2008, at: <https://wcd.coe.int/ViewDoc.jsp?p=&id=1304019&direct=true>.

⁴⁶ European Court of Human Rights, V Chamber, *Mandet v. France*, n. 30955/12, 14 January 2016.

⁴⁷ E. MERCKX, *Mandet v. France: Child's "duty" to know its origins prevails over its wish to remain in the dark*, available at <https://strasbourgobservers.com/2016/02/04/mandet-v-france-childs-duty-to-know-its-origins-prevails-over-its-wish-to-remain-in-the-dark/#comments>.

⁴⁸ European Court of Human Rights, *Mandet v. France cit.*, para. 57.

⁴⁹ In this case the role of surrogate is probably less relevant, unless for health problems arisen during the gestation.

⁵⁰ A. CAMERON, V. GRUBEN, F. KELLY, *De-anonymising sperm donors in Canada: some doubts and directions*, in *Canadian Journal of Family Law/Revue canadienne de droit familial*, vol. 26, 2010, p. 110.

⁵¹ I. GLENN COHEN, *Sperm and Egg Donor Anonymity: Legal and Ethical Issues*, in L. FRANCIS, *Oxford Handbook of Reproductive Ethics*, Oxford University Press, 2016, available at: <http://ssrn.com/abstract=2600262>, p. 15.

⁵² *Ibidem*.

Much more controversial would be the disclosure of the donor's and/or the surrogate mother's identity.

A possible normative solution could be drawn from the ECtHR's case-law on anonymous and secret birth. The decisions held in the cases *Odièvre v. France* and *Godelli v. Italy* demonstrate that the Court, in order to balance the right to anonymity of the birthmother and the right to trace origins of the progenies, requires an independent and impartial mechanism aimed at verifying, at the request of the interested person, the mother's availability to waive anonymity⁵³. It is up to the birthmother to decide whether (and to what extent) to renounce to confidentiality.

It should be noted, nevertheless, that anonymous and secret birth is usually permitted to preserve not only the mother's and child's health during pregnancy and birth, but also to avoid abortions, abandonment other than under the proper procedure and even infanticide⁵⁴. However, anonymity has clearly not the same meaning under ART normative discipline. Moreover, as BOTTIS well explains, 'withholding a secret from someone represents the power over that person and a conflict of interest between two parties'⁵⁵, especially when the information is kept reserved "'from the very person" [it] is directly related'⁵⁶. If one considers that 'the donor-conceived person [could] insist that the biological father's/donor's personal data are simultaneously 'her' data as well'⁵⁷, the request to get information would not be described as the access to another individual's personal data and would be consequently more easily satisfied.

Nevertheless, 'the rules pertaining to anonymity versus mandated identification are likely to be at the center of [the donor's] evaluation in the majority of cases'⁵⁸. For this reason, while a 'prospective' regime, requiring for future donations/surrogacies the disclosure of all identifying information, would certainly not interfere with a surrogate/donor's right to anonymity⁵⁹, the legitimacy of the opening of past records ('retrospective' regime) is much more debated. A possible solution would be permitting retrospective access to identifying information, allowing the donors/surrogates to veto any potential contacts with the resulting children (so-called 'contact veto system'⁶⁰). However, according to TOBIN, 'the compulsory release of identifying information against the will of a donor, even where a contact veto is in place and the donor conceived individual faced the threat of criminal sanction should this veto be breached, still remains problematic, [as it would] violate the guarantee of anonymity given to the donor in circumstances where it was a condition precedent to him making the donation in the first instance'⁶¹.

Therefore, States are certainly called under international law to regulate the access to identifying information for future donations/surrogacies, but they should maintain the option of confidentiality for donors and surrogates who have been guaranteed anonymity, while encouraging them to disclose their identity.

⁵³ European Court of Human Rights, *Godelli v. Italy cit.*, para. 57; Grand Chamber, *Odièvre v. France*, n. 42326/98, 13 February 2003, para. 49.

⁵⁴ European Court of Human Rights, *Odièvre v. France cit.*, para. 45.

⁵⁵ M. BOTTIS, *Anonymization of Sperm Donors for artificial insemination: an international data protection law perspective*, in *Icfai University Journal of Environmental & Healthcare Law*, vol. 8, 2009, p. 75.

⁵⁶ *Ibidem*.

⁵⁷ *Ivi*, p. 80.

⁵⁸ I. GLENN COHEN, *op. cit.*, p. 16.

⁵⁹ In fact, those who do not wish to be identified may simply choose not to donate their gametes or be a surrogate.

⁶⁰ S. ALLAN, *Access to information about donors by donor-conceived individuals: A human rights analysis*, in *Journal of Law and Medicine*, vol. 20, 2013, p. 669.

⁶¹ J. TOBIN, *op. cit.*, p. 26.

6. *The duty to tell the truth as a parents' responsibility: what role for the State?*

The right to know genetic and biographic origins certainly implies the right to be informed about the modalities of the conception, namely the recourse to one of the mentioned third party reproduction techniques. We can define this profile as 'the right to the truth': it represents an essential prerequisite to the exercise of the right to know personal origins.

In this field, children of heterosexual recipient parents are more exposed to a denial of their right than children of same-sex and single parents. In fact, secrecy surrounding the use of third-party ART is quite common among heterosexual couples and it is driven by the fear of possible negative impact on family bonds, especially between the parent who lacks a genetic link with the child and the child himself/herself⁶². On the contrary, different factors explain the reason why lesbian and gay parents are more used to reveal not only the recourse to gamete donation and surrogacy, but also the identity of the donor and the surrogate mother as well⁶³.

Does 'the right to the truth' imply a duty upon the States to 'enforce' the information? Clearly, if the answer were in the positive, a mechanism making information available to the resulting child only at his/her request, would not be sufficient for the State to fulfill its obligation. Rather, an 'active registry' would be necessary: 'a more muscular kind of intervention, which (...) would itself contact the child at age eighteen to let him or her know that he or she was donor conceived and allow (but not force) him or her to receive information about the donor'⁶⁴.

A similar solution, however, does not appear desirable, as it would probably create more problems than those it aims to address. Therefore, 'the right to the truth', as a *conditio sine qua non* for the exercise of the right to know the genetic and biographic origins, rests upon the parents who will freely decide whether to be honest with their children about the nature of their conception or not. In this field, States play only a residual role, being called to encourage recipient parents to reveal children the methods of conception, and to possibly supply counselling services to assist and guide all the people involved in the disclosure process.

7. *Conclusions*

The respect of the right to know genetic and biographic origins requires rules imposing to donors and surrogates the disclosure (and, to some extent, the constant updating) of non-identifying data, including medical records, and even of identifying information, at least for donation and surrogacy to come. Donors' and/or surrogates' anonymity deserves a more stringent protection, when they have been guaranteed confidentiality, but States are arguably called to envisage mechanisms to encourage the release of information, as well as sustaining social parents and children in the process of disclosure the means of conception.

⁶² A. CAMERON, V. GRUBEN, F. KELLY, *op. cit.*, pp. 130-131.

⁶³ N. CAHN, *op. cit.*, pp. 14 ss.

⁶⁴ I. GLENN COHEN, *Rethinking sperm-donor anonymity: of changed selves, nonidentity, and one-night stands*, in *Georgetown Law Journal*, vol. 100, 2012, p. 447.

The recourse to ART is usually justified by the parents' desire to have (at least partial) genetic connection with their progenies, as 'a biological connection to the future' is considered 'a vital part of the identity of adults'⁶⁵. Similarly, and even *a fortiori*, children might feel the analogous desire to define their 'biological connectedness to the past'⁶⁶, as well as other elements of their personal history, including pre-natal experiences, as in the case of surrogacy.

States are thus called to guarantee that the use of technologies to create children and families is accompanied by clear normative provisions, fairly guaranteeing rights and interests of everybody.

⁶⁵ N. CAHN, *op. cit.*, p. 19, quoting J. LINDEMANN NELSON, *Cloning, Families, and the Reproduction of Persons*, in *Valparaiso University Law Review*, vol. 32, 1998, p. 719.

⁶⁶ *Ibidem*.